# 2017 SENATE HUMAN SERVICES

# SCR 4010

# 2017 SENATE STANDING COMMITTEE MINUTES

**Human Services Committee**
Red River Room, State Capitol

SCR 4010
2/22/2017
Job Number 28532

☐ Subcommittee
☐ Conference Committee

| | |
|---|---|
| Committee Clerk Signature | Jena Bellamy for Marne |

**Explanation or reason for introduction of bill/resolution:**

A concurrent resolution requesting the Legislative Management to consider studying the status and importance of coordinated palliative care to develop solutions, tools, and best practices for providing better patient-centered care and information to North Dakotans with chronic diseases.

**Minutes:**

4 Attachments

**Chair J. Lee:** Brought the hearing on SCR 4010 to order, all members were present.

**(0:01:00-0:03:30) Senator Dick Dever, District 32**: Introduced the resolution. 50 years ago cancer was a death sentence. Hospice came about and it was about managing the dying process. Palliative care is about managing the living process. How do you deal with it? I was asked by the Cancer Society to introduce this resolution. It calls for a study; a good question would be where do we see that study going? Palliative care specialists in the bigger hospitals, and it's an important concept even if it only develops public knowledge.

**(0:03:40-0:04:45) Chair J. Lee**: It isn't an all-inclusive word, but I think sometimes comfort care is an easier concept. Hospice is still an important player, integrated with palliative care. People are people, not objects for medicines.

**(0:05:10-0:09:00) Kim Kuhlmann, American Cancer Society Action Network:** read testimony in favor of the resolution, please see attachment #1.

**Kim Kuhlmann:** Palliative care is focused around patient care. It can be pain management, nutrition, physical activity, how can we improve quality of life. Usually involves a team and is about what the patient needs. Cancer Alzheimer's, diabetes can all benefit from palliative care. (Attachment #2)

**Senator Clemens:** Isn't there a lot of information now, this study to provide more information for patients and caregivers, what's the main purpose in 3 points.

**Kim Kuhlmann:** There is information available on palliative care. Part of the large problem is people hear palliative care and hear hospice, think they're terminal, and not going to survive. Lots of education needs to be done so that if approached about palliative care, they aren't scared away. North Dakota Cancer Coalition has done a preliminary palliative care survey. They asked hospitals, assisted living, long term care association, hospice, and home health care if they are offering palliative care and what does that mean. Part of the problem is that palliative care at one facility isn't the same at others, we don't know that the means. You might get different standards of care; part of the study is to find out what is happening around palliative care in North Dakota. How can we make sure that patients are getting consistent care when they go from one facility to another?

**(0:13:40-0:19:00)** Discussion on the reason for a legislative study instead of working with the providers. The idea of a central body that's objective as compared to the hospitals studying it amongst themselves. Where the legislative involvement is, maybe another venue would be better. Who pays for palliative care? ACS is working on Federal legislation; part of the reason for introducing study it's a lot easier to start with in the states for creating an opportunity. There are other states who have passed and they used model language.

**Senator Kreun:** Where are the greatest needs to have palliative care, there are certain parts that have very good care, how are we to administer this.

**Kim Kuhlmann:** I think that's part of the study what's the need, what's out there. It's going to be different from urban to rural, make sure both have what they need.

**(0:20:15-0:24:20) Mark Jorritsma, Executive Director of Family Policy Alliance of ND please see attachment #3.**

**Senator Clemens:** What percentage of palliative care recipients are terminal patients?

**Mark Jorritsma:** The short answer is I don't know; I can find out. I imagine it's pretty high, the challenge there is that when people refuse palliative care, they're in a depressed state. The ability to make the kind of decisions that need to be made is greatly diminished. A large percentage of those who would benefit are in a state of mind like that.

**(0:27:15-0:36:15)** Committee conversed on the topic of palliative care and if it should be in the legislation as a study, which is under government responsibility or if it would be better suited to be held in the private sector.

**(0:37:00-0:39:00) Erica Cermak, Government Affairs Representative MD-MN Alzheimer's Association: Please see attachment #4. Gave statistics from attachment #4A.**

**Senator Anderson:** 265 physicians in the MN-ND area?

**Erica Cermak:** No that's, nationwide, I'll provide this fact sheet.

**No opposition or neutral testimony.**

**Chair J. Lee: Ended public hearing on SCR 4010.** I suggest we ask for some additional information on this before we make a decision.

# 2017 SENATE STANDING COMMITTEE MINUTES

**Human Services Committee**
Red River Room, State Capitol

SCR 4010
3/1/2017
Job Number 28582

☐ Subcommittee
☐ Conference Committee

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|---|---|
| Committee Clerk Signature | Marne Johnson |

**Explanation or reason for introduction of bill/resolution:**

A concurrent resolution requesting the Legislative Management to consider studying the status and importance of coordinated palliative care to develop solutions, tools, and best practices for providing better patient-centered care and information to North Dakotans with chronic diseases.

**Minutes:**

4 Attachments

**Chair J. Lee:** Brought the public hearing on SCR 4010 to order. All members were present.

**Cheryl Rising, Legislative Liaison, ND Nurse Practitioner Association (2:30-6:40) Testified in favor, please see attachment #1.**

**Trina Kaiser, Family Nurse Practitioner, (7:18-14:30) Testified in favor, please see attachment #2.**

**Senator Piepkorn:** What's the relationship between hospice care and palliative care?

**Ms. Kaiser:** All hospice care involves palliative care, but not all palliative care is hospice care; hospice care patients are deemed to be in the last 6 months of life, and not pursuing aggressive treatment of their disease. In palliative care, we see patients that are hospice appropriate, but they don't want to give up yet.

**Chair J. Lee:** Children are the exception, we do allow curative treatment for children in hospice, but otherwise insurances do not allow treatment if you're getting hospice.

**Senator Piepkorn:** In my experience, palliative care is the last stop.

**Ms. Kaiser:** We would like to change that; it is very difficult when you're in a crisis situation. It's hard to have difficult conversations with patients and family. It's a process, with ongoing conversation that's something that happens in the clinic setting, their condition is progressing; the conversation is progressing. But we have people discharged and coming back. But yes, that is the perception most of the time.

**Chair J. Lee:** We understand the need for palliative care, we want to know what the government role is? We aren't the providers; we don't want to legislate palliative care. I would like to see the providers you mentioned get together.

**Ms. Kaiser:** I don't know exactly what the advisory council would propose; one thing is education, because people don't understand what palliative care is.

**Chair J. Lee:** That might be more true of the public. Information from the medical schools on palliative care training, **please see attachment #3**. We were told earlier that only 265 doctors were trained in this; that was 2014-2015 and one program in the country. I think the public isn't quite tuned into it.

**Brenda Iverson, Director of Community Relations, Hospice of Red River Valley (22:40):** There's confusion on difference, here is a graphic, **please see attachment #4,** palliative care is offered early on. Hospice is given for 6 months. 28% patients are served by hospice for 7 days or less, that is part of the value that palliative care brings. Our organization started a separate service line a year ago, 118 people served, 30 patients transitioned to hospice. 3 examples: preventing hospital visits, decreasing medication burden, and improving health status. I hope that helps with the difference between hospice and palliative care.

**Steve Slabik, Director of Finance, Hospice of the Red River Valley (29:20):** I hear your dilemma; I think the state Department of Health could help coordinate the effort in the state, could look at alternative reimbursement methods, because the state is a payor of medical claims. There's a lot of money spent on a few patients at the end of their life, there could be a cost savings if there would be a switch in the financial incentives.

**Senator Anderson:** How is palliative care reimbursed?

**Mr. Slabik:** It's reimbursed very poorly; it requires a physician or a nurse practitioner to visit. The other services, nurse calls, chaplain visits, there's no reimbursement. It's the medical model of reimbursement, a visit equals money.

**Chair J. Lee:** I wonder if that's federal or state.

**Chair J. Lee: Closed the public hearing.**

# 2017 SENATE STANDING COMMITTEE MINUTES

**Human Services Committee**
Red River Room, State Capitol

SCR 4010
3/2/2017
Job Number 28656

☐ Subcommittee
☐ Conference Committee

Committee Clerk Signature

**Explanation or reason for introduction of bill/resolution:**

A concurrent resolution requesting the Legislative Management to consider studying the status and importance of coordinated palliative care to develop solutions, tools, and best practices for providing better patient-centered care and information to North Dakotans with chronic diseases.

**Minutes:**

5 attachments

**Chair J. Lee:** Brought the committee discussion to order. All members were present.

**Chair J. Lee:** I was inspired, I don't feel like government should intrude, but we want to make sure there's enough information about this. most folks don't pay attention until it comes to them. How about if the stake holders that had interesting information yesterday, became a task force rather than it being a Legislative Management Study, since the Legislature couldn't plan a decent license plate. I called Pat Traynor, from the Dakota Medical Foundation, he supports this idea, so we'd have some administrative support from the Dakota Medical Foundation (DMF), if we needed it. I made a list, **please see attachment #1,** read the list **(1:30-2:30)** I sent a message to Patricia Moulton, of the Center for Nursing, asking if she'd like to be a facilitator, she'd like to be engaged, she's going to talk to her board. Lynette Dickson, Center for Rural Health, they've just completed a statewide palliative care needs assessment, she'd like to be engaged; that could be a core group, they could elect their own chair, DMF could provide administrative support, we can say if we want to that they shall provide a report to Legislative Management. But I think we should just keep let them do their work.

**V-Chair Larsen:** I embrace that opportunity, I don't like growing government, I don't like big committees; Rod St. Aubyn's group, they just did it. They brought some good information.

**Senator Anderson:** another example is the Opioid Coalition. Last session a couple successful bills came out of that, this time I was here with state wide peer review, which came out of that Coalition. I don't think any of us disagree with palliative care; what they're asking for is more attention. I have to agree that's not really the role of government.

**Chair J. Lee:** We should add the Department of Health to that list, all of those entities are organizations. These people are all self-supporting, this can be conference calls. So folks don't have to travel.

**Senator Clemens: I make a motion do not pass.**
**V-Chair Larsen: Second.**
**A roll call vote was taken. Motion passes 7-0-0.**
**Sen. Anderson will carry.**

**Senator Anderson:** I think when you look at these resolutions the easiest choice is to pass them out. I think in these cases the committee stepped up.

**Chair J. Lee: Closed the hearing on SCR 4010.**

**Attachments 2, 3, 4, and 5 were provided for committee's reference via email.**

Date: 3/2 2017

Roll Call Vote #: 1

## 2017 SENATE STANDING COMMITTEE
## ROLL CALL VOTES

**BILL/RESOLUTION NO.** 4010

Senate Human Services Committee

☐ Subcommittee

Amendment LC# or Description:

Recommendation:
☐ Adopt Amendment
☐ Do Pass ☒ Do Not Pass ☐ Without Committee Recommendation
☐ As Amended ☐ Rerefer to Appropriations
☐ Place on Consent Calendar

Other Actions:
☐ Reconsider ☐

Motion Made By Sen. Clemens Seconded By Sen. Larsen

| Senators | Yes | No | Senators | Yes | No |
|---|---|---|---|---|---|
| Senator Judy Lee (Chairman) | X | | Senator Joan Heckaman | X | |
| | | | | | |
| Senator Oley Larsen (Vice-Chair) | X | | Senator Merrill Piepkorn | X | |
| | | | | | |
| Senator Howard C. Anderson, Jr. | X | | | | |
| | | | | | |
| Senator David A. Clemens | X | | | | |
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| Senator Curt Kreun | X | | | | |
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Total (Yes) 7 No 0

Absent 0

Floor Assignment Sen. Anderson

If the vote is on an amendment, briefly indicate intent:

## REPORT OF STANDING COMMITTEE

**SCR 4010: Human Services Committee (Sen. J. Lee, Chairman)** recommends **DO NOT PASS** (7 YEAS, 0 NAYS, 0 ABSENT AND NOT VOTING). SCR 4010 was placed on the Eleventh order on the calendar.

**2017 TESTIMONY**

**SCR 4010**

SCR 4010
Attach #1
2/22

North Dakota Senate Human Services Committee

February 22, 2017

9:00 AM

SCR 4010

Chairman Judy Lee and members of the Senate Human Services Committee, my name is Deb Knuth and I am the North Dakota Government Relations Director for American Cancer Society Cancer Action Network. Thank you for allowing me to speak to you today.

Palliative care is a topic of utmost importance to the American Cancer Society and ACS CAN. You will hear experts speak on the finer points of palliative care access and delivery today, but perhaps let me set the stage by letting you know where we stand: we believe palliative care should be an essential component of every person's cancer journey. Palliative care has a different goal in mind compared to curative treatments: it seeks to address the anxiety, pain, and suffering that interfere with a person's quality of life during cancer treatment. It is something that should be afforded cancer patients starting from their point of diagnosis forward and not reserved to those persons late in treatment or later in life. Basically, palliative care serves to treat THE PERSON while other specialists may be focusing on the cancer itself. Palliative care might include hospice care, but it is in no way limited to hospice care, and it can be something that is complementary and concurrent with curative treatments OR when a cure is no longer the patient's preference. It is something that should be afforded all individuals with cancer regardless of their diagnosis or prognosis.

Just as with our other public policy issues, ACS CAN views palliative care as a field of patient-centered care in need of further innovation, support, and access. We are asking you to join our efforts, to help BE the solution to the question "what good are advances in medicine if they aren't being delivered to the people who need them?"

I ask the Senate Human Services Committee for a yes vote on SCR 4010. On behalf of the American Cancer Society Cancer Action Network, thank you for your time this morning. I hope that each of you will stay connected with us at ACS CAN as we change the course of history in our quest for a cancer-free world.

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7/22

Are there any questions?

ACS CAN, the nonprofit, nonpartisan advocacy affiliate of the American Cancer Society, supports evidence-based policy and legislative solutions designed to eliminate cancer as a major health problem. ACS CAN works to encourage elected officials and candidates to make cancer a top national priority. ACS CAN gives ordinary people extraordinary power to fight cancer with the training and tools they need to make their voices heard. For more information, visit **www.acscan.org**

SCR 4010
#2
2/22
Pg.1

## Is palliative care right for you?

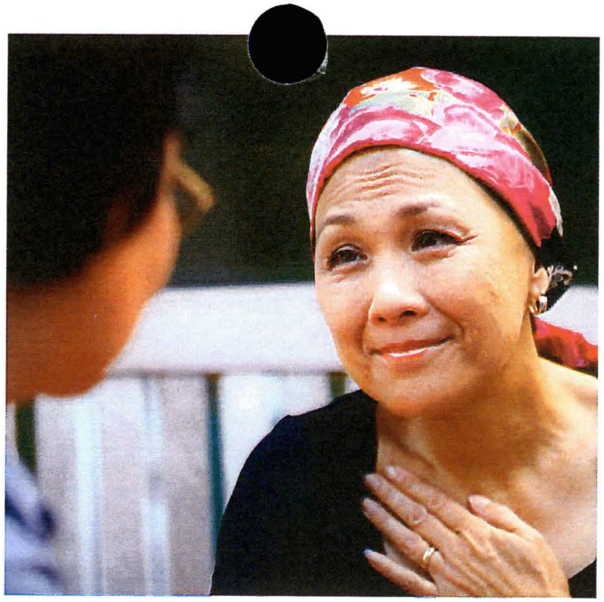
Palliative care may be right for you or a loved one if you are having symptoms or side effects that interfere with your quality of life. These might include pain, shortness of breath, fatigue, depression, loss of appetite, or nausea.

## Who provides palliative care?

Your oncology doctors and nurses may provide palliative care as part of your cancer treatment to help reduce your symptoms or side effects. In addition, they may also ask for help from a palliative care health professional or team to work with them and provide expert symptom management, extra time for communication, help with advanced care planning, and help in navigating the health system. The palliative care team may include specially trained doctors, nurses, chaplains/spiritual counselors, and social workers. Pharmacists, nutritionists, massage therapists, and others might also be part of the team. Many hospitals and cancer centers have these specialized teams available for consultation as part of the comprehensive cancer care services they provide.

## Where is palliative care provided?

Palliative care is provided in a variety of settings – including hospitals and community cancer centers – where patients and survivors frequently receive cancer care. Palliative care may also be available in long-term care facilities, through hospice, and even in the home.



## How can you receive palliative care?

Ask for it! Tell your doctor, nurse, family, and caregivers that you are interested in having palliative care along with your cancer treatment to help address symptoms and other concerns for yourself or your loved one. Most insurance plans, including Medicare and Medicaid, cover palliative care services. If costs are a concern, a social worker or other member of the palliative care team can help you.

## Where can you find more information?

If you have questions about palliative care, call your American Cancer Society at 1-800-227-2345, 24 hours a day, seven days a week. You can visit **cancer.org** and **getpalliativecare.org** for further information. An online tool that helps prepare you for talking with your doctors about your quality of life and decision making is also available at **prepareforyourcare.org.**

## Will palliative care be available when you need it?

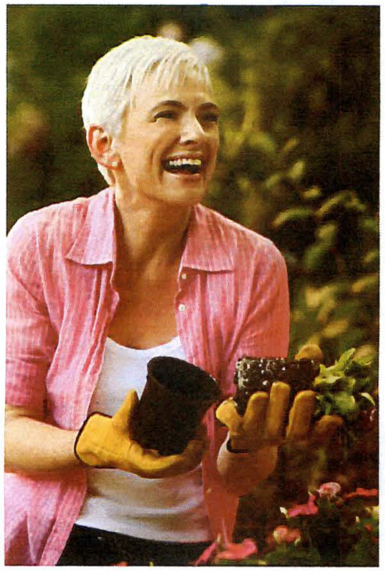
Palliative care is a growing specialty, but these services are not always available to those who need them. The American Cancer Society's advocacy affiliate, the American Cancer Society Cancer Action Network (ACS CAN), is working to improve access to palliative care for all people facing cancer and other serious illnesses. ACS CAN supports proposals to fund research and training that will help broaden delivery of quality palliative care to all care settings, while also increasing the number of specialized palliative care-trained doctors, nurses, and other health professionals. For more information, visit **acscan.org/qualityoflife.**

SCR 40D
#2
2/22
Pg. 2

## What is palliative care?

Palliative care, also called supportive care, can improve the quality of life for cancer patients and their families by focusing on relieving the pain, stress, and other symptoms of cancer and its treatment.

Palliative care can be given at any age and any stage of disease. It can be provided from the time of diagnosis and continue along with curative treatment. Palliative care uses a team approach to bring together your cancer doctor with other doctors and nurses who specialize in treating symptoms. They consider what is most important to you and help you make decisions about your care that are right for you.



No. 9643.04 - Rev. 06/14
Models used for illustrative purposes o

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Cancer Action Network℠ American Cancer Society®

The American Cancer Society's nonprofit, nonpartisan advocacy affiliate, the American Cancer Society Cancer Action Network℠ (ACS CAN), is working to make certain that palliative care is available to all people with cancer and their families. For more information, visit **acscan.org.**

# Improving Quality of Life through Palliative Care

*Treating the Person as well as the Disease*

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Cancer Action Network℠ American Cancer Society®

SCR 4010
Attach #3
2/22

# Testimony on Senate Concurrent Resolution 4010
## by Family Policy Alliance of North Dakota
## February 22, 2017

Good morning Chairman Lee and honorable members of the Senate Human Services Committee. My name is Mark Jorritsma, Executive Director of Family Policy Alliance of North Dakota. I am testifying on behalf of our organization and the thousands of our constituents across our great state for you to please recommend a "DO PASS" on Senate Concurrent Resolution 4010.

This resolution seeks to ask Legislative Management to consider, "studying the status and importance of coordinated palliative care to develop solutions, tools, and best practices for providing better patient-centered care and information to North Dakotans with chronic diseases." In other words, our interpretation of this resolution is that we as North Dakotans understand the value of a person's life in our state and want to affirm that value from birth to natural death. When someone we love faces the fear of a terminal diagnosis—and all the emotions and decisions that come with it—more than ever, they need to know that we believe their life is worth fighting for and that we have a system in place to deliver much-needed palliative care to them.

Some states, including Colorado and Washington, D.C. most recently, have voted to abandon those with terminal illnesses to hopelessness and death through assisted suicide. They consider that this is the only real option. However, this resolution would affirm that we in North Dakota want to be known as a state that provides the best quality care to all our citizens, no matter their health condition or disability, rather than a state that abandons its citizens in their time of greatest need.

Many people do not fully understand what palliative care actually is. Palliative care is patient and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering. Palliative care throughout the continuum of illness involves addressing physical, intellectual, emotional, social, and spiritual needs and facilitating patient autonomy, access to information, and choices of treatment.[1] Palliative care focuses on treating the person, as well as the disease, helps provide support and inclusion for family members, and improves quality of life and survival.

Did you know that some of the biggest barriers to getting patients with serious illnesses access to palliative care are:

- ✓ Lack of knowledge and understanding about palliative care;
- ✓ Variability in access based on geographic location, physician training, and services offered;
- ✓ Inadequate workforce to meet the needs of patients and families; and

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[1] National Hospice and Palliative Care Organization, available at http://www.nhpco.org/palliative-care-4.

4010
#3
2/27

- ✓ Insufficient research to guide and measure quality of care.[2]

This resolution is aimed at studying precisely these types of barriers to help our sickest patients get access to the best care for them and their families. So please render a "DO PASS" recommendation on Senate Concurrent Resolution 4010 so that we can:

- ✓ Identify specific barriers in North Dakota preventing access to palliative care for patients with serious or long-term illness;
- ✓ Take the first steps in establishing a palliative care consumer and professional information program ensuring that comprehensive and accurate information about palliative care is available to the public; and
- ✓ Not waste time focusing on assisted suicide, as other states are doing, but get to work eliminating barriers to effective treatment, so that North Dakotans with the most serious illnesses can get access to the care they and their families need.

Thank you for your time. I am ready to stand for any questions you might have.

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[2] *See* Increased Access to Palliative Care and Hospice Services: Opportunities to Improve Value in Health Care, The Milbank Quarterly (Sept. 2011), available at http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3214714/ .

2/22/17 SCR 4010 Attachment #4 pg 1

# Testimony
## Senate Concurrent Resolution 4010 – Erica Cermak, on behalf of Alzheimer's Association, ND/MN Chapter
## Senate Human Services Committee
## Senator Judy Lee, Chairwoman
## February 22, 2017

Madame Chair and members of the Committee, my name is Erica Cermak, I am the Government Affairs Representative for the North Dakota-Minnesota Chapter of the Alzheimer's Association. Thank you for the opportunity to speak with you today in support of SCR 4010.

The Alzheimer's Association is the world's leading voluntary health organization in Alzheimer's disease care, support, and research. Our Chapter proudly serves the States of North Dakota and Minnesota.

Alzheimer's is a progressive, neurodegenerative and fatal disease for which there currently is no treatment or cure. More than 5 million Americans, including 14,000 in North Dakota, are living with Alzheimer's disease. Sadly, North Dakota leads the nation in Alzheimer's deaths per capita, making it the 3rd leading cause of death in our state.

Palliative and hospice care – with a focus on managing and easing symptoms, reducing pain and stress, and increasing comfort – can improve both the quality of care and quality of life for those living with advanced dementia.

Although the availability of palliative and hospice care is growing, the need is growing faster and quality care remains a concern. To date, nationwide, it is estimated that more than 6,000 full-time health professionals are needed to serve the current demand in hospice and palliative care programs.

**Palliative Care in the US:**

- In 2000, less than one-quarter of US hospitals had a palliative care program, by 2013, that number increased to three-quarters.
- A recent survey of nursing homes indicated that while three quarters report having hospice care, less than half report having some sort of palliative care program.
- In the 2014-15 academic year, only 265 physicians were trained in hospice and palliative medicine by accredited programs.

The Alzheimer's Association believes that palliative care is a crucial piece of patient centered care that should be offered to people living with Alzheimer's and other dementias beyond what is utilized during end of life hospice care

SCR 4010 would be an important tool to begin to understand how palliative care is addressed in North Dakota, how it can be utilized further, and where there may be opportunities for improvements within the State for palliative care.

Thank you for the opportunity to speak to you today. I would be happy to answer any questions you may have.

*Statistical information obtained from:
http://act.alz.org/site/DocServer/2016_PCHETA_Fact_Sheet.pdf?docID=50905

2/22/17 SCR 4010 Attachment #4A pg 1

alzheimer's association®

factsheet

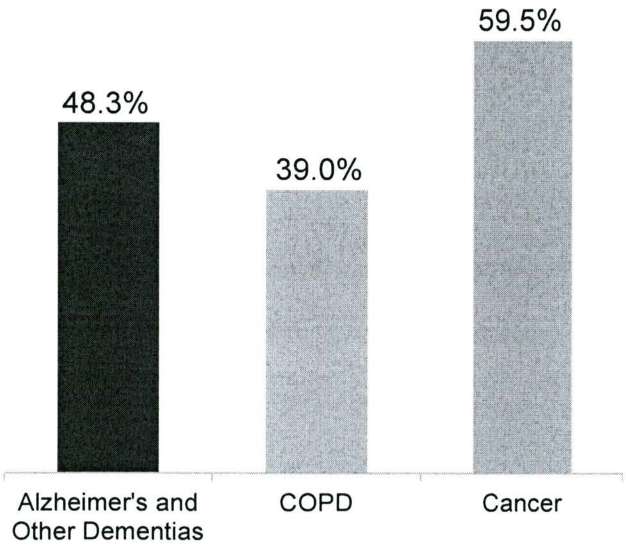
MARCH 2016 alz.org®

# PCHETA and Alzheimer's Disease

**Palliative and hospice care – with a focus on managing and easing symptoms, reducing pain and stress, and increasing comfort – can improve both the quality of care and quality of life for those with advanced dementia.**

- Observational studies have shown that as many as half of nursing home residents with advanced dementia have documented pain in the last weeks of life – and about a third have difficulty breathing or swallowing, or suffer from agitation.
- Individuals with advanced dementia who are enrolled in hospice have a lower rate of dying in the hospital, a lower rate of hospitalization in the last 30 days of life, and better symptom management.
- A recent study shows that nursing home residents with dementia who receive palliative care at the end of life, compared with those who do not receive such care, are:
  - up to 15 times less likely to die in a hospital
  - nearly 2.5 times less likely to have a hospitalization in the last 30 days of life
  - up to 4.6 times less likely to have an emergency room visit in the last week of life.
- Families of individuals with dementia who are enrolled in hospice have a greater satisfaction with patient care.

**Percentage of Seniors Receiving Hospice Care at Time of Death, by Condition**



**People with Alzheimer's and other dementias rely heavily on hospice at the end of life.**

- Of all people living with dementia, 18.6 percent are currently in hospice care – a higher percentage than other chronic conditions.
- Among seniors in hospice care, one in every six has a primary hospice diagnosis of Alzheimer's or other dementia.
- Nearly half of all people with dementia die in hospice care.

2/22/2017 SCR 4010 #4A pg 2

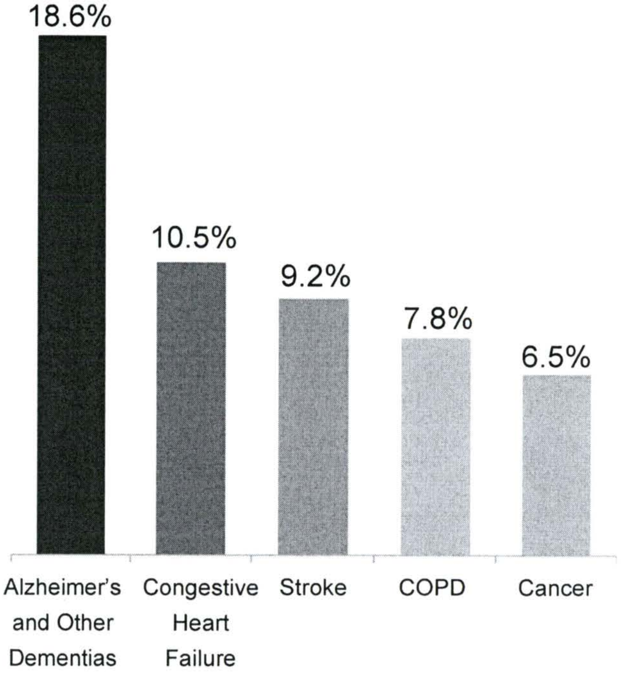
### The availability of palliative and hospice care is growing, but the need is growing faster – and the quality of the care remains a concern.

- In 2000, less than one-quarter of U.S. hospitals had a palliative care program. By 2013, that had increased to three-quarters.
- Hospice care is now available in nearly three-quarters of surveyed nursing homes, but less than half of surveyed nursing homes report having some sort of palliative care program.
- Of those nursing homes with a palliative care program, only 42 percent include consultation by a physician certified in hospice/palliative care, and only 28 percent had a designated palliative care director.
- In the 2014-15 academic year, only 265 physicians were trained in hospice and palliative medicine by accredited programs. An expert Task Force concluded that 6,000 more full-time health care professionals are needed to serve current needs in hospice and palliative care programs.

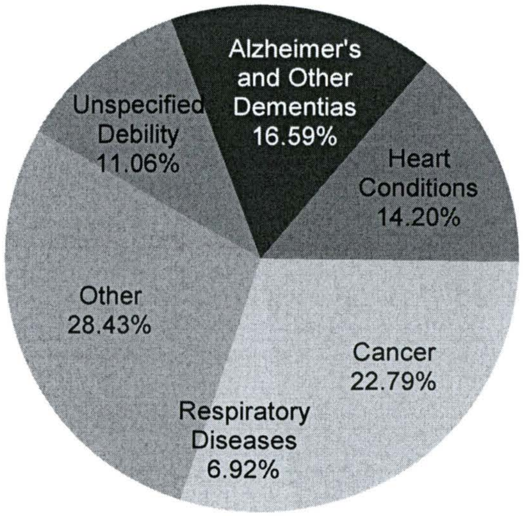
### To increase the availability and quality of care, the *Palliative Care and Hospice Education and Training Act* (PCHETA) would:

- Establish palliative care and hospice workforce training programs for doctors, nurses, and other health professionals.
- Create a national education and awareness campaign to inform patients, families, and health professionals about the benefits of palliative care and available services and supports.
- Enhance research on improving the delivery of palliative care.

### Percentage of Seniors with Specified Condition Who Are Receiving Hospice Care, 2014



### Hospice Users, by Primary Hospice Diagnosis



SCR 4010
Attach
#1
3/1
Pg. 1

NDNPA
NORTH DAKOTA
Nurse Practitioner Association

Senate Human Services Committee
3/1/2017

Madam Chairman Lee and Committee Members:
I am Cheryl Rising, Family Nurse Practitioner (FNP) and Legislative Liaison for the North Dakota Nurse Practitioner Association (NDNPA). I am here to give input on Senate Concurrent Resolution 4010 regarding palliative care.

Palliative care is knowledge and skill that APRNs and other providers should learn. It is developed and refined over time. This care does help with relief in suffering (physical, emotional, and spiritual). You will see improved patient outcomes and higher patient satisfaction. There is a Center to Advance Palliative Care and the definition in use is improving quality of life for both the patient and the family. Palliative care also includes discussion of goals of care and advance care planning. With APRN's working with people with many serious life threatening illness, palliative care is there to help prevent and relieve suffering. A recent article published in The Journal for Nurse Practitioner, vol 12, N0 10 November/December 2016 is an excellent resource. It is stated in the article if you would not be surprised that a patient would die in the next year, then palliative care should be considered.

Palliative care will discuss plan of care, code levels and other wishes of the individual and help get advance directives documented if not prior. It is so important to do this prior to a crisis. If you wait and ask about care a person or family wants during a crisis, you will almost always over treat. Hospice is another aspect of palliative care and focuses on the life closure and bereavement support

4010
#1
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We do have palliative care education in our APRNs programs. Also, there are certifications that APRNs can obtain in palliative care. One of the NPs that gave input for today is working in Internal Medicine and is certified in palliative care.

In the above mentioned, article, there are several references sited that can be used for education by health care providers. If there is a concern about health care providers not being educated on this subject I would recommend that we develop a task force with individuals from NDNPA, Medical Association, BON, Board of Pharmacy, NDNA, Hospice and Long Term Care. This group could look at the recommendations and standard of care and develop a plan to improve standards and care and education in this area in ND.

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## North Dakota Senate Human Services Committee

## March 1, 2017

## SCR 4010

Chairman Lee and members of the Senate Human Services Committee, my name is Trina Kaiser. I have been a Family Nurse Practitioner for several years and in the past year I have been working in the specialty of Palliative Care. I would like to talk about what palliative care involves, why it is important, necessary, and beneficial. I will also point out some of the barriers to receiving palliative care services.

### Palliative Care - Definition

"Palliative care is care for adults and children with serious illness, like cancer, that focuses on relieving suffering and improving quality of life for patients and their families, but is not intended to cure the disease itself. It provides patients of any age or disease stage with relief from symptoms, pain, and stress, and should be provided along with curative treatment."

Reference: Putting Quality of Life in Prime Time: Palliative Care Resource Guide, developed by the Center Advance Palliative Care and the American Cancer Society, June 2015

### Important Components

- May be used early in the course of illness at the same time as treatments intended to prolong life
- Uses a team approach to address needs of patient and family
- Offers symptom relief
- Does not intend to hasten or prolong death
- Includes psychological and spiritual components of care
- Provides support to patient and family to cope with illness and grief
- Helps patients to live as well as possible for as long as possible

### Why are palliative care services needed?

- Aging population
- Advances in medicine
- Approximately 90 million Americans have serious illnesses
- 2/3 of health care spending is utilized on the sickest 10% of the patient population
- Often experience inadequate symptom control, lack of continuity in care, poor communication among their health care providers
- High burden placed on caregiver

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The **Institute of Medicine 2013 Quality Cancer Care Consensus Report** suggests that palliative care begin at diagnosis, continue during cancer treatment and last in to survivorship for symptom management and relief of suffering

**World Health Organization statement:** Palliative care is most effective when considered early in the course of the illness. Early palliative care not only improves quality of life for patients but also reduces unnecessary hospitalizations and use of health-care services.

## Palliative Care Benefits

- Earlier palliative care referral was associated with fewer emergency room visits, fewer hospitalizations, and fewer hospital deaths in the last 30 days of life.

  Reference: Hui D, Kim SH, Roquemore J, Dev R, Chisholm G, Bruera E. Impact of timing and setting of palliative care referral on quality of end-of-life care in cancer patients. Cancer (2014) 120(11):1743–910.1002/cncr.28628

- Early introduction of palliative care, concurrently with disease-specific treatment can improve quality of life for patients, mood, and survival

  Reference: Temel JS, Temel JS, Greer JA, Muzikansky A,et al. Early palliative care for patients with metastatic non-small-cell lung cancer. N Engl J Med 2010; 363:733–742.

- Palliative care can improve patient symptoms in an outpatient setting.

  Reference: Yennurajalingam S, Urbauer DL, Casper KL, Reyes-Gibby CC, Chacko R, Poulter V, Bruera E. Impact of a Palliative Care Consultation Team on Cancer-Related Symptoms in Advanced Cancer Patients Referred to an Outpatient Supportive Care Clinic. J Pain Symptom Manage. 2011 Jan;41(1):49-56.

- In a study comparing standard care with ongoing palliative care in patients with advanced cancer and a prognosis of 6 to 24 months to live, palliative care resulted in improved patient quality of life, satisfaction with care, and decreased symptom severity.

  Reference: Zimmermann C, Swami N, Krzyzanowska M, et al. Early palliative care for patients with advanced cancer: a cluster-randomised controlled trial. Lancet, May 2014, Vol 383, Issue 9930

- Association was demonstrated between early palliative care and receiving less intensive medical care, improved quality outcomes, and lower costs at the end of life.

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Reference: Scibetta C, Kerr K, Mcguire J, Rabow MW. The Costs of Waiting: Implications of the Timing of Palliative Care Consultation among a Cohort of Decedents at a Comprehensive Cancer Center. J Palliat Med. 2016 Jan;19(1):69-75.

Potential barriers to receiving palliative care:

**BARRIER #1**: Limited access

Availability

- Palliative care services are increasing but one third of hospitals report no palliative care services of any kind and access to palliative care services in the outpatient or community setting is much more limited

Accessibility

- Patient with serious medical conditions have difficulty getting in to palliative care clinic setting for variety of reasons including limited mobility, transportation issues, multiple other appointments, or simply too ill

**BARRIER #2:** Lack of knowledge / awareness

Data from Public Opinion Strategies national survey of 800 adults age 25 and older conducted in 2011 **found 70% of Americans are "not at all knowledgeable" about palliative care**

92% of respondents state they would be likely to consider palliative care for loved one if they had a serious illness

92% of respondents say it is important that palliative care services be made available at all hospitals for patients with serious illness and their families

Reference: Center to Advance Palliative Care. 2011 Public Opinion Research on Palliative Care

**BARRIER #3**: Limited workforce

- Lack of trained professionals
- Time constraints

I ask the Senate Human Services Committee for a yes vote on SCR 4010 to start an initial process for evaluating and addressing some of these potential barriers so that this vulnerable population of North Dakota residents may benefit from palliative care services. Thank you.

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**University of North Dakota, School of Medicine and Health Sciences – Training in palliative care**

1st and second year students – 96 hours of curriculum with relevance to end of life or palliative care

[illegible] year med students

Family Medicine clerkship:

- 3 hours directed lectures
- additional discussion in Social Determinants of Health Videoconferences & other conferences

Internal Medicine clerkship

- 2 hours of relevant lecture
- One week palliative care elective
- Opportunities for one day palliative care elective day
- Participation in 5-10 palliative care conferences / week over the 8 week rotation

4th year med students – one month elective in palliative care

Family Medicine residency (Bismarck)

- multiple lectures
- on-site experience with in patient and outpatient palliative care team
- elective rotation in Palliative Care

Family Medicine residency (Minot)

- One faculty member is board certified in Palliative care. She lectures regularly on the topic.
- Residents are observed talking to patients and families about palliative care and then formally critiqued.

Internal Medicine residency (Fargo)

- Two hours of core didactic conferences
- One month elective clinical rotation in palliative care with a physician board-certified in palliative care
- Regular interaction with the Sanford Palliative Care consult service

Psychiatry

- Exposure during one month internal medicine rotation to 5-8 palliative care conferences / week
- Substantial exposure during the mandatory Geriatric Psychiatry rotations
- Some additional discussion during case reviews and psychotherapy supervision where relevant.

Surgery

- On line SCORE (Surgical Council on Resident Education) curriculum incorporates several modules in palliative care each covered twice during training.
- Real time exposure to palliative care through consults with the palliative care teams
- They have access to palliative care information through several other avenues, which are not mandatory but encouraged. These include didactic lectures at each of the core sites, computer access through the AMA IPM (introduction to practice of medicine) and American College of Surgeons and the American Board of Surgery websites.

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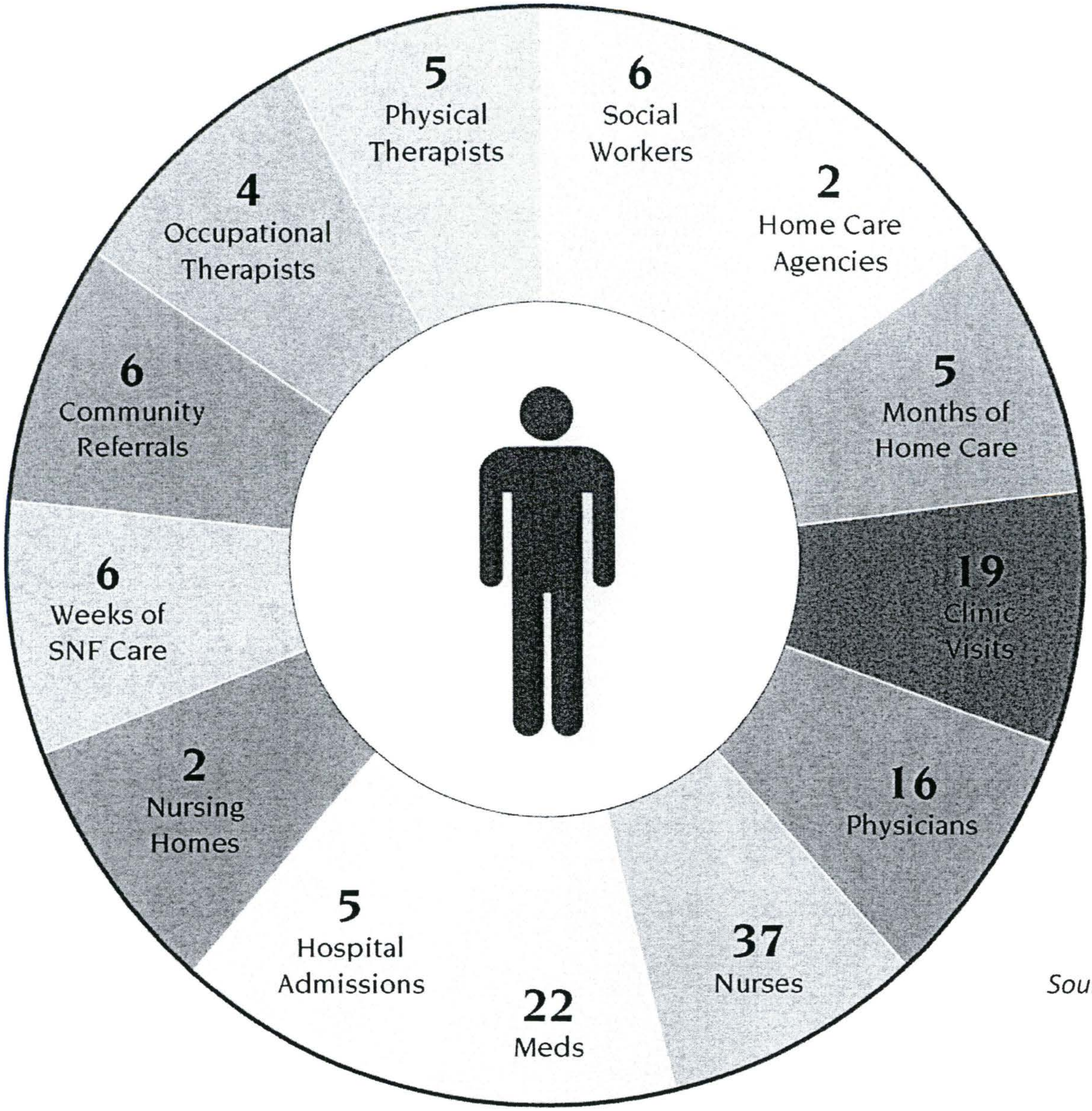
# A Year in the Life of a Patient



**5** Physical Therapists

**6** Social Workers

**2** Home Care Agencies

**5** Months of Home Care

**19** Clinic Visits

**16** Physicians

**37** Nurses

**22** Meds

**5** Hospital Admissions

**2** Nursing Homes

**6** Weeks of SNF Care

**6** Community Referrals

**4** Occupational Therapists

*Source: Johns Hopkins, RWJ 2010 (G Anderson)*

HOSPICE
RED RIVER VALLEY

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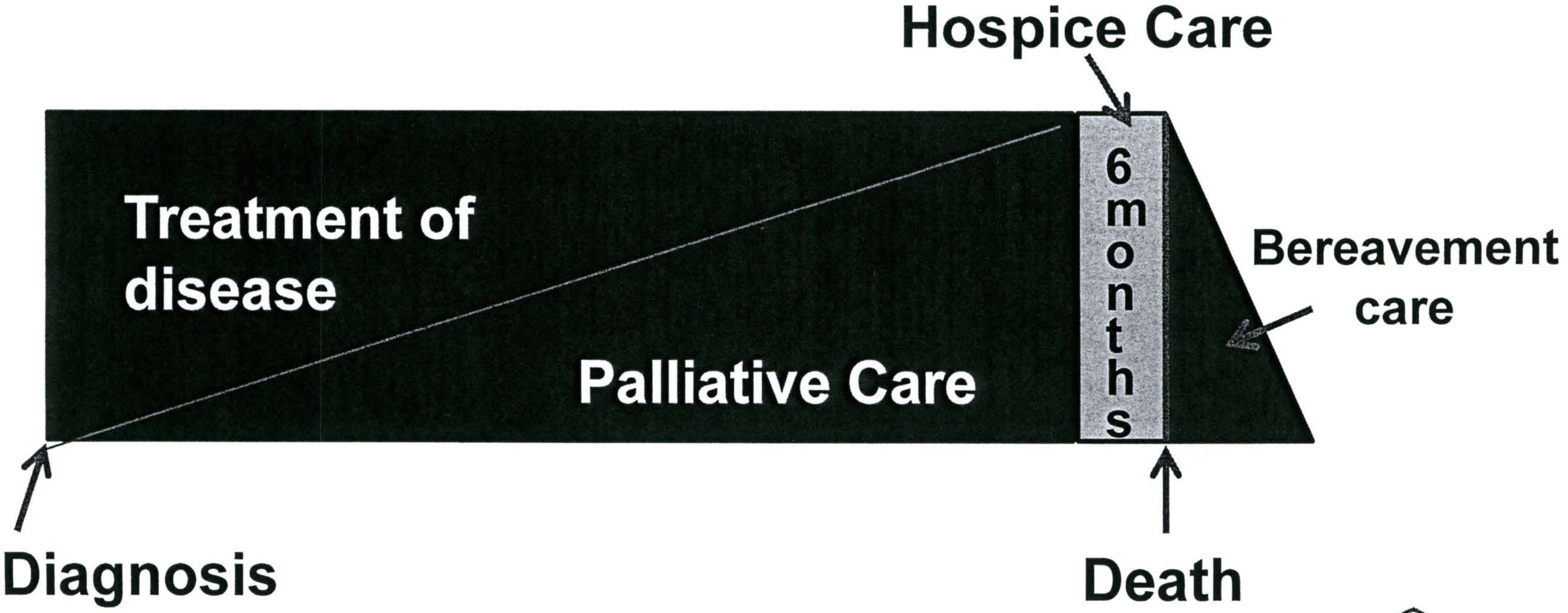
# Palliative Care vs. Hospice Care

- All hospice care is palliative; not all palliative care is hospice.



HOSPICE
RED RIVER VALLEY

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# Palliative Care Stakeholders

Dakota Medical Foundation

Hospice of Red River Valley

Center for Nursing

Center for Rural Health

ND Medical Association

ND Hospital Association

ND Long Term Care Association

Nurse Practitioners Association

Board of Nursing

School of Medicine & Health Sciences

American Cancer Society

Dept. of Health

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| | | | | | | | |
|---|---|---|---|---|---|---|---|
| **Ave Maria Village**<br>**Policy/Procedure Manual:** | | | | **Section**<br>**Page:** | | | |
| **Department:** | | **Resident Services** | | | | | |
| **Subject:** | | **Comfort Care** | | | | | |
| **Procedure Manual** | | | | | | | |
| | | | | | | | |
| **Date Originated:** | **03/01** | **11/01** | **05/02** | **01/03** | **10/05** | **11/06** | **09/08** |
| | **11/09** | | | | | | |
| | | | | | | | |

## POLICY:

Comfort Care will be implemented upon a physician's order when it is determined a resident's status is terminal.

## PURPOSE:

1. To promote the resident's comfort.
2. To maintain the resident's dignity and respect.
3. To provide support to both the resident and family

## EQUIPMENT/SUPPLIES: AS NEEDED.

## PROCEDURE:

1. The Primary Care Nurse will obtain a physician's order for Comfort Care and for continuation or discontinuation of medications.
2. Comfort Care Guidelines will include the following and will be initiated at the Primary Care Nurse's discretion, unless ordered differently by physician or requested differently by the resident or family.
   a. Assess and provide medication for comfort/pain management
   b. Oxygen Administration per cannula or mask if the resident is in distress.
   c. Nasopharyngeal or Oropharyngeal Suctioning
   d. Diet altered or discontinued. Food and fluids offered as resident allows.
   e. Medications as ordered.
   f. Bedrest
   g. Occupational, Physical, and Restorative Therapy discontinued.
   h. Oral Care every hour.
   i. Reposition with back care every hour.
   j. Check for incontinence every hour and change if needed. Discontinue Toileting Program
   k. Vital Signs per nurses discretion.
   l. Family Update with significant changes.

3. Documentation
   a. Care Plan
   b. Interdisciplinary Progress Notes.

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# Senate Concurrent Resolution No. 4010

- Hospice of the Red River Valley
    - ADC approx. 290 patients
    - Region of coverage 29 Counties ND & MN
    - 1,582 patient served in 2016
    - More than half of our patients live in a long-term care facility
    - More than half of our patients have a diagnosis other than cancer
        - 35% Cancer
        - 20% Dementia (#2)
        - 14% Advanced Cardiac Disease
        - Pulmonary, renal, liver, neurologic, etc
    - Served our first hospice patient in 1981
    - Started palliative care program with pilot 4/16
- How does palliative care differ from hospice care
    - Both are specialized medical care for those living with a serious and/or life-limiting illness. The care focuses on providing relief from the symptoms and stress of a serious illness, wherever that person calls home. Palliative care is the only health care program that can follow a patient into any setting.
    - Palliative care services are appropriate for any patient living with a serious illness, no matter the patient's prognosis. Individuals with chronic or serious illnesses, those receiving aggressive, curative care and those nearing the end of their lives, are all candidates for palliative medicine
    - Hospice care is a specialty subset of palliative care. It is intensive comfort care available to anyone with an incurable illness and a prognosis of six months or less if an illness runs its normal course.
    - Both palliative care and hospice care focus on enhancing quality of life for these patients and their families by addressing their medical, emotional, spiritual and grief needs.
    - Palliative care is reimbursed with NP, MD or MSW visits to the patient. RN, social worker, chaplain if involved are not reimbursable.
    - Hospice includes a Medicare / Medicaid/insurance benefit including the interdisciplinary approach to care for the patient and family. Benefit covers medications, med equipment, inpatient respite care, CCN, volunteers, bereavement, ongoing spiritual support for patient & family, nurse on call 24x7
    - Palliative care reimburses for MD, NP or MSW only.

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  - Unlike home health, patient does not need to be home bound to receive these services.
  - With palliative care, typically half of these patients will get better and are discharged. The other half continue to be supported with palliative care.
  - As patients illness progresses, the palliative care team works to ensure goals and preferences are clear, documented within an AD and communicated with family.
  - Palliative care allows the person to continue with curative treatment while getting support, helping them navigate their care
  - Examples of how we support with palliative care
    - Symptom mgmt.: Pain, problems breathing, nausea, constipation, fatigue, insomnia, depression/anxiety
    - Medical Decision Making: Completing an AD, Patient & Family goals & wishes
    - Clarifying medications & treatments
    - Promoting communication with the health care team
    - Transition to hospice when appropriate
- Why do we support this resolution?
  - We need legislative support for palliative care in the state.
    - Programs supporting palliative care. Education regarding palliative care, interest in the palliative care specialty (shortage of pal care providers)
      - Outcomes for this group are especially important as a majority of the seriously ill fall into the top 5 percent of the population that accounts for 50 percent of total health care expenditures.
      - Serve patients in their homes. Prevent unnecessary hospitalizations, proactive approach versus reactive. Decrease hospital LOS & improve hospital bed utilization. More appropriate usage & choice of testing according to prognosis. More informed choices by the patient & family. Making choice before crisis improves utilization. Continuity of care.
      - Palliative care – see them in SNF, home, etc. Most readmissions occur within 3 days of hospitalization. We can help manage this gap, helping keep them home.
    - Reimbursement for care, including full ID team
    - Caring for those with serious illness in their homes decreases burden on the healthcare systems, allows patient centered-care, reduces cost
    - Education to HCP
      - Misunderstandings in community & medical community

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        - Patient-centered care
        - How to engage in these conversations
        - When to consider palliative & hospice care
            - Our efforts in education. University, medical, general communities
- Our experience in seeing the gap in care first hand
    - Patient referred to hospice who are not yet eligible due to aggressive tx, > 6 mo's diagnosis, patient/family refusal
    - Palliative care allows us to establish a relationship with the patient and family, helping guide them before there is a crisis
    - Almost 200 people didn't get our care at end of life last year as they died before we could help them
    - 28% of patients in 2016 were served 7 days or less
        - A day in the life of a patient in the last year of life
- What we know about the continued myths, misunderstandings
- Our experience with palliative care
    - 119 admitted patients to RRVPC since started
    - 32 patients were admitted to hospice from RRVPC
- Share a couple of stories from our palliative care program
    - Preventing hospitalizations, increasing hospice usage:
        - We cared for a lung cancer patient in his 50s, his prognosis was poor but he continued to receive chemotherapy. He said at the beginning of the palliative care visits that he wanted to do everything possible to stay alive as long as possible, including hospitalizations. Palliative care nurse made visits every couple of weeks, discussing goals for end of life and reviewing how his health was changing. He continued to decline, his symptom burden increased, and after seeing his oncologist decided to go on hospice. Had this patient not had the education and support from palliative care, he likely would have continued his treatment and ended up in the hospital when his health declined. Instead he was able to die comfortably at home with his family around him.
    - Decreasing medication burden:
        - An 89 year old patient with a dx of heart failure was living at home with her son and daughter in law. She was taking 18 different medications at the start of palliative care. With careful medication review and with the input of the medical director, we were able to reduce her pill burden by 22%, which pleased the patient and the family. She was also eligible for hospice while on palliative care, preventing her from hospitalization when her heart failure worsened. Her wish was to remain at home, and we have been able to grant this for her.

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- Improving Health Status:
    - A patient in his 50s was living at home alone, struggling with symptoms of heart failure, diabetes and several other co morbidities. He was hospitalized 3-4 times within 3 months for fluid overload. He had several wounds on his legs, and was not able to leave his apartment. His health was extremely poor, but he was not ready for hospice. Our palliative care team went in to see this patient, helped him with his medications and provided education on diet and he still did not improve, as he was non-compliant with his medications and diet. Education continued with nursing visits on hospice and after some time he was agreeable to hospice services and very much appropriate due to his symptoms. He was admitted to hospice, and his health actually improved due to the diligent nurse visits, CNA assistance, and availability of medical care 24/7. He improved so much that he was eventually discharged from hospice, and now continues to live at home with the help of the palliative care nurse. He has been able to leave his apartment on occasion, and his quality of life has improved significantly. He has not been hospitalized since before his hospice admission, in part due to the working relationship between his cardiologist and the palliative care nurse.

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Senate Human Services Committee
HCR 4010
March 1, 2017
Red River Room
3:30 PM

Palliative care is the specialized treatment of patients with life limiting or life altering illnesses. That focus is providing multidisciplinary care and support of both the patient and family at any time during their illness. There is a gray misconception that palliative care is "end of life" care when in reality it is so much more. While hospice is available for patients no longer seeking active medical treatment with a life expectancy of 6 months or less palliative care is focused on providing care for patients at any time during their terminal illness regardless of if they are seeking active treatments.

When a patient is referred to our palliative care team, we start by getting to know the patient and their family, where they are from, were they married, how many children they have, what they did for a living. By getting to know the patient on a more personal level it helps to gauge what their values and goals are and most importantly how they want to live out the rest of their life. We then work with the patient and all the patient's other providers to develop a care plan keeping the patient's goals in mind. We strive to ensure that all the patient's needs are met whether they be medical, emotional, psychological or spiritual.

Unfortunately, at the current time, palliative care is not available in all locations so there is a large number of patients who do not have access to, or knowledge of, where they can receive this specialized care.

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Tracy Freidt
Palliative Care Specialist

SCR 4010
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**NDLA, S HMS - Johnson, Marne**

[redacted]
| | |
|---|---|
| | Lee, Judy E. |
| | Wednesday, March 01, 2017 11:52 AM |
| **To:** | NDLA, S HMS - Johnson, Marne |
| **Subject:** | FW: ND S HCR 4010 |
| **Attachments:** | Palliative Care Report to Director, RI DOH, FINAL.pdf; Palliative Care in Florida-report.pdf |

Copies, please

Senator Judy Lee
1822 Brentwood Court
West Fargo, ND 58078
home phone: 701-282-6512
e-mail: jlee@nd.gov

**From:** Deb Knuth
**Sent:** Wednesday, March 1, 2017 10:45 AM
**To:** Lee, Judy E. <jlee@nd.gov>
**Cc:** Bill < >; Kimberly Kuhlmann <
**Subject:** ND S HCR 4010

[redacted]**UTION:** This email originated from an outside source. Do not click links or open attachments unless you know they are safe.

Senator Lee: Kim Kuhlmann told me that when she testified at this hearing for SCR 4010, you had some concerns. I hope that this email answers some of your questions regarding why we would like the study resolution to pass. We believe the legislators' key power is the ability to convene and get people to the table. Without that ability to gather people together and participate, it's difficult to build consensus and continuity.

There are at least fourteen states that have passed palliative care legislation and those states house a website within their department of health or another state agency. Attached is information from Florida and Rhode Island.

The main reason for involving the state department of health as opposed to us doing it, is the infrastructure they already have in place throughout the state to be able to reach all corners, and the ability they have to raise awareness and educate the public, patients, caregivers and medical professionals about the benefits of palliative care services.

We could try to do it, but involving the power of the state is critical to coordinate and empower any recommendations that come from the task force to advance the awareness, availability and utilization of palliative care in any state.

For your information, we asked a couple of palliative care professionals from St. Alexius to come to this afternoon's hearing to testify. I also have a letter from another hospital's palliative professional to pass along. Thanks! Deb

[redacted]**Knuth** | North Dakota Government Relations Director
American Cancer Society Cancer Action Network, Inc.

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**acscan.org**

Cancer Action Network
American Cancer Society
acscan.org

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# Palliative Care Needs and Services in Rhode Island

{A Report of the Rhode Island Palliative Care and Quality of Life Interdisciplinary Advisory Council* – 2 November 2015}

In 2013, the Rhode Island Palliative Care and Quality of Life Act was signed into law, creating "The Rhode Island Palliative Care and Quality of Life Interdisciplinary Advisory Council" ("the Council") under the aegis of the Rhode Island Department of Health ("HEALTH"). In the language of the Act,

> "The purpose of the palliative care consumer and professional information and education program shall be to maximize the effectiveness of palliative care initiatives in the state by ensuring that comprehensive and accurate information and education about palliative care is available to the public, healthcare providers, and healthcare facilities."

The following initial report was developed by the Council to assist HEALTH in efforts to improve the health of Rhode Islanders who live with serious and life-threatening illness.

## Defining Palliative Care

The Center to Advance Palliative Care defines Palliative Care as *a specialized medical care for people with serious illnesses* focusing on relief from the symptoms and stress of serious and life-threatening illness. Palliative Care addresses physical, emotional, spiritual and psychosocial suffering, with the goal of improving quality of life for patient and caregivers. Palliative care is provided by specially-trained teams of physicians, nurses, and other specialists who collaborate with patients' "regular" healthcare providers to deliver an extra layer of supportive care. Palliative care is appropriate at any age and any stage of a serious illness, and is compatible with curative treatment.

## Challenges and Emerging Solutions

Dramatic changes have occurred in the mix of causes of death in the past century. Fewer deaths are now attributable to infection, and more to chronic illness, with a concomitant increase in average length of life. As people live longer, developing and managing chronic illnesses, many experience periods of functional dependency – some prolonged – before death, presenting challenges – and new choices – for healthcare during serious, protracted illnesses, and at the end of life.

Several "solutions" have emerged to address these challenges over time, including skilled nursing facilities, dedicated hospice inpatient units (hospital-based or freestanding), and the provision of supportive nursing services (and other services) at home. Palliative care may be delivered as an integral part of each of these solutions, each of which has distinct strengths and weaknesses as a context for the provision of palliative care.

The mix of settings in which palliative care is delivered has changed over time, shaped by a variety of forces, with the result that the mix of "places of death," e.g., hospital, skilled nursing

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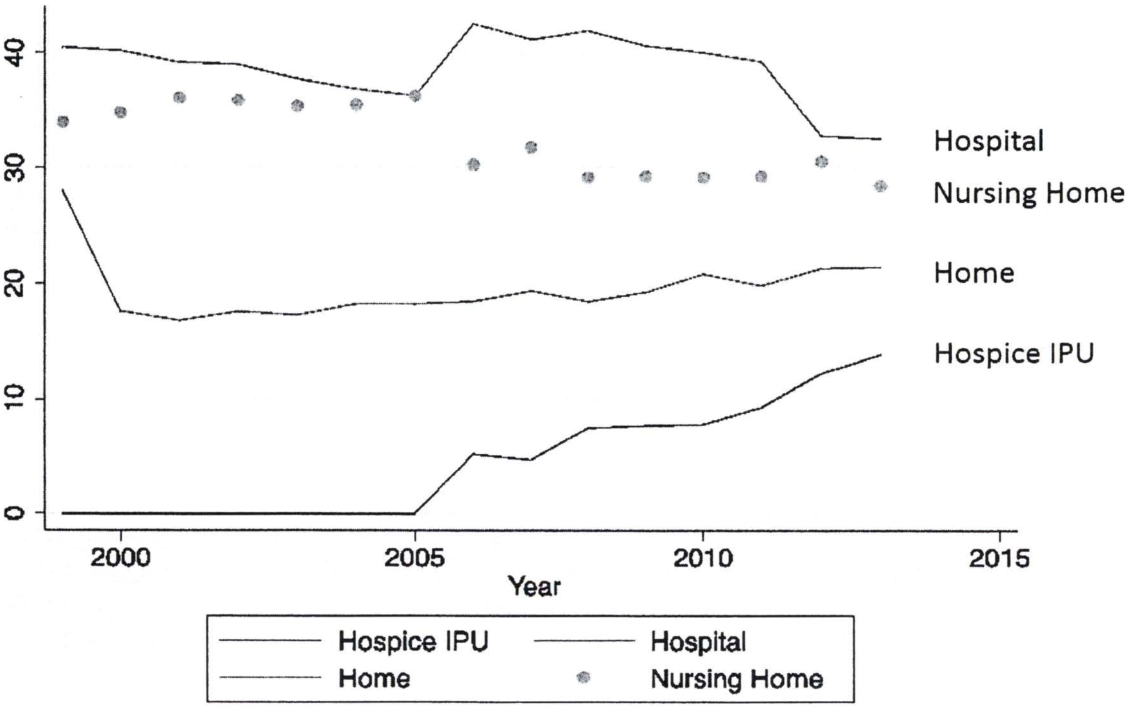
facility, inpatient hospice unit, and home has changed over time, as well. In Rhode Island, for example, the mix has changed rather dramatically over the past 15 years or so (Figure 1).

Figure 1. Place of death, Rhode Island residents, 2000-2013



Source: Rhode Island Vital Records.

The proportion of deaths occurring in hospitals and skilled nursing facilities has decreased, as the proportion of deaths at home or in hospice inpatient units has increased. Greater use of hospice inpatient units for end-of-life care is especially striking.

## Notable Issues

Thus far, the Council has explored several issues relevant to the design and provision of palliative care in the State of Rhode Island, namely, *hospital-based palliative care, advance care-planning, and opioid use in pain management*, and on the basis of these explorations is prepared to make preliminary recommendations "to maximize the effectiveness of palliative care initiatives in the state."

### *Hospital-Based Palliative Care*

A growing resource for improving the quality of care of patients with serious and life-threatening illness is *hospital-based* palliative care. At present, however, there is no standard (therefore reliable) way to track the provision of palliative care in acute care settings, other than

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those dedicated entirely to the provision of palliative care, such as hospice inpatient units. Accordingly, and in line with its mission, the Council surveyed palliative care staff employed by acute care hospitals in Rhode Island in 2015. The following questions were asked:

1. Does the hospital have a palliative care team?

2. What is the volume of palliative care consults in a year?

3. Which of the disciplines are members of that palliative care team?

4. Is the palliative care team certified by JACHAO?

Preliminary survey results are displayed in Table 1:

Table 1: Preliminary results of a hospital-based survey to assess the provision of palliative care services

| Hospital System/ Hospital | Palliative care team? | Professions represented on the palliative care team | | | | Comments |
|---|---|---|---|---|---|---|
| | | Nurse practitioner? | Social worker? | Spiritual care? | Physician? | |
| **Lifespan/** | | | | | | |
| Rhode Island | Yes | X | X | X | X | |
| Hasbro | Yes | | | | | |
| The Miriam | Yes | X | X | X | X | |
| Newport | Yes | X | | | X | |
| **Care N.E./** | | | | | | |
| Kent | Yes | X | | X | X | |
| Memorial | Yes | | | | X | |
| Women & Infs | Yes | X | X | X | X | |
| Butler | Yes | | | | X | |
| **Chartercare/** | | | | | | |
| Fatima | Yes | unk | unk | unk | unk | Did not respond |
| Roger Williams | Yes | X | X | X | X | JACHAO cert. |
| **Other hospitals** | | | | | | |
| Landmark | No | n/a | n/a | n/a | n/a | |
| South County | No | n/a | n/a | n/a | n/a | |
| Westerly | No | n/a | n/a | n/a | n/a | |
| Providence VA | Yes | unk | unk | unk | unk | Did not respond |

Of the 14 hospital units assessed, 11 had a designated palliative care team (Table 1). We estimate that these 11 teams had performed about 2,600 consults in the preceding 12 months. Each team had a physician member with board certification in hospice and palliative medicine. Only one had JACHAO advanced certification of the palliative care team, *per se*.

### *Advance Care-Planning*

One important tool in the provision of palliative care is advanced care planning. When the Council reviewed the use of "Medical Orders for Life Sustaining Treatment" ("MOLST") in Rhode Island, we found that few seriously ill patients had completed a MOLST form.

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In short, few seriously ill patients had "advance directives" – specific directions about what treatments to use and not to use at the end of life.

*Opioid Use in Pain Management*

Opioids are frequently used to control pain (and other symptoms) at the end of life. The Council notes that the state is currently faced with important concerns about the abuse and diversion of prescription opioids. (Nationwide, this issue has led some states to require mandatory continuing medical education for prescribers of opioids, especially long acting opioids, in persons with non-cancer pain.) The Council believes, however, that these important concerns must be balanced against the need to assure appropriate access to opioids for persons who are dying, and for those patients living with serious illnesses requiring management of serious pain.

## Preliminary Conclusions and Recommendations

*Access to Palliative Care*

Rhode Island leads the nation in that nearly every hospital has hospital-based palliative care services. Substantial progress has been made in ensuring that hospitalized patients have access to these services, but there is still important work that needs to be done. Two efforts are worthy of further consideration:

- Expand *outpatient palliative care services*. (Doing so would meet the needs of persons in the community who are not eligible for, or who do not choose, hospice services.)

- Improve *timely referral to hospice services*. (Doing so would assure optimal use of a wide variety of palliative care services.)

  Action items:

  1) Develop a HEALTH web site incorporating one or more videos in multiple languages to explain palliative care services, including how they complement and enhance existing hospice services in the state.
  2) Educate hospitalists and physicians in the community about the value of palliative care services and hospice, and the potential benefits of referral.
  3) Work with existing hospital-based palliative care teams to expand community-based services.
  4) Expand the involvement of spiritual care and other disciplines in existing palliative care programs.
  5) Assure access to palliative care for pediatric patients.
  6) Assure access to palliative care, not just for the terminally ill, but for all patients with serious, protracted illnesses (various types of chronic illnesses).
  7) Integrate palliative care services into patient-centered medical homes.

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*Advance Care Planning*

Many seriously ill patients in Rhode Island do not have advance directives.

- Expand the use of MOLST.

  Action Items:

  1) The **Continuity of Care** form is the primary document used to transmit information as patients transition through the health care system and we believe it would be important to note the presence of MOLST on the form. We suggest that on page 2 and page 5 of the **Continuity of Care** form, the box addressing advance directives and code status be changed to read:

     "Does the patient have an Advanced Directive? **Yes**___ **No** ___"

     "Code Status: **Full** ___ **DNR**___ **CMO**___"

     "Does the patient have MOLST? **Yes**___ **No**___"

  2) The HEALTH website could be a valuable source of information on MOLST and we suggest that in addition to the Public Health Grand Rounds Power Point and the link to the MOLST form, the following be added:

     a) The FAQ on MOLST developed by Maureen Glynn

     b) A "fireside chat" (video) on palliative care and MOLST

  3) While the MOLST form needs to be in English so providers can read it, it would be helpful to have instructions in other languages available. For example, consider the following information from the *2013 American Community Survey* on languages spoken in the State of Rhode Island:

| | |
|---|---|
| Population 5 years and over | 995,757 |
| Speak only English | 78.9% |
| Speak a language other than English | 21.1% |
| Spanish or Spanish Creole | 11.0% |
| Other Indo-European languages | 7.2% |
| Asian and Pacific Island languages | 2.1% |
| Other languages | 0.8% |

  4) Incorporate MOLST into Current Care.

  5) Update HEALTH surveyors on MOLST so that as they go into facilities they can be certain to look at facility policies, procedures, and compliance with the MOLST legislation.

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6) Continue to promote the completion of the **Rhode Island Durable Power of Attorney for Health Care** form for all Rhode Islanders over the age of 18.

*Access to Opioids*

Concerns about prescription opioid abuse and diversion may impinge on the availability of opioids for the management of serious pain in terminally ill and seriously ill patients.

- HEALTH should pursue a *balanced* policy to address issues of opioid prescribing, one which includes: 1/ when to avoid the prescribing of opioids; *and* 2/ the importance of opioids being prescribed for dying persons and those patients living with cancer and other serious illnesses.

  Action Items:

  1) Consider mandatory continuing education for the appropriate prescribing of opioids, striving for the balance suggested by the Council. Models are available from other states such as Washington State.

  2) Include Palliative Care experts when considering changes in policies that may impact the availability of opioids for dying persons and those patients living with cancer and other serious illnesses.

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*** Members of the Council**

| | |
|---|---|
| Edward V. Martin, MD, MPH | [Chair] Medical Director, Home and Hospice |
| Maria Barros, RN | Director of Clinical Services, Nursing Placement, Inc. |
| The Rev. Marie Carpenter | Director of Eldercare Ministries,<br>American Baptist Churches of Rhode Island |
| Linda Del Vecchio-Gilbert, DNP | Associate Professor,<br>New England Institute of Technology<br>Nursing Department |
| Linda M. Dziobek, RN | Partnership to Reduce Cancer in Rhode Island |
| Nancy Roberts, MSN, RN | President and CEO<br>VNA of Care New England Health System |
| Angela Taber, MD | Palliative Medicine Physician<br>Miriam and Rhode Island Hospitals |
| Joan M. Teno, MD* | Professor of Health Systems, Policy, and Practice<br>Brown University School of Public Health<br>*Dr. Teno was a member through June of 2015 |